CHAPTER III.6. COST OF SPINA BIFIDA

Clicking on the sections below will take you to the relevant text.

CHAPTER III.6. COST OF SPINA BIFIDA

III.6.A Background

This chapter contains a discussion of the methods used and the results of estimating the direct medical costs incurred by individuals with spina bifida and the results of the analysis.[1] It does not include information on elements such as indirect medical costs, pain and suffering, lost time of unpaid caregivers, etc. The reader is referred to Chapter I.1 for a discussion of the cost estimation methods and cost elements that are relevant to all benefits estimates. In addition, Chapter III.1 contains information regarding the special characteristics of developmental defects, and a list of chemicals that may cause developmental abnormalities.

The costs presented in this chapter were current in the year the chapter was written. They can be updated using inflation factors accessible by clicking on the sidebar at left.

Link to Chapters I.1 and III.1
Link to inflation factors

III.6.A.1 Description

Spina bifida occurs when the neural tube, from which the brain and spinal cord develop (central nervous system), fails to close properly. Depending on where closure fails to occur, portions of the brain, spinal cord, and nerves connected to them will not function properly. If failure to close occurs on the lower portion of the spinal cord, then the bowel, bladder or sexual organs will be affected. Failure at mid-level may cause paralysis or malfunction of the arms and legs. Anomalies at higher levels may affect the brain. In most spina bifida cases, the normal flow of cerebrospinal fluid is also blocked (Arnold-Chiari malformation), which would result in hydrocephalus unless treated (Waitzman et al., 1996).

Some common disabilities and medical problems associated with spina bifida are:

- sight problems, including atrophy of the optic nerve in 17 percent of children and strabismus in 42 percent of children (Gaston, 1985);
- dysfunction in the arms in 45 percent of children (Turner, 1986);

[1] "Costs" in this chapter refer to direct incremental per capita medical costs, unless otherwise noted.

- epilepsy in 20 to 30 percent of children (Bartoshesky et al., 1985); and

- bladder dysfunction in most children (McLone, 1983).

III.6.A.2 Concurrent Effects

Approximately six percent of children with this anomaly have malformations outside the central nervous system. These commonly affect the diaphragm, esophagus, and kidneys. Cleft lip and palate are also associated with spina bifida (Waitzman et al., 1996). Additional malformations outside of the central nervous system include:

- pressure sores and skin problems in 70 percent of adolescents and young adults (Blum et al., 1992);

- curvature of the spine in 15 percent of children (Samuelsson and Eklof, 1988); and

- weight substantially over the norm in 30 to 50 percent of children (Thomas et al., 1987).

III.6.A.3 Causality

Spina bifida is associated with prenatal exposure to sulfonamides and antihistamines, maternal folate deficiency, and maternal diabetes. Chemicals that interfere with the development of the neural crest and fold during embryogenesis may cause spina bifida (Waitzman et al., 1996). Table III.1-1 in Chapter III.1 lists numerous chemicals associated with developmental abnormalities in human and/or animal studies.

Link to Chapter III.1, Table III.1-1

III.6.A.4 Treatment and Services

Treatment may begin before birth if diagnosis occurs during pregnancy. Lab tests are now available that provide an indication of whether spina bifida is likely. Ultrasound may be used to confirm the test results. Cesarean delivery may be used to prevent damage to the infant. The spinal canal defect is usually closed surgically shortly after birth. Approximately 90 percent of infants receive a ventriculaoperitoneal shunt to carry fluid from the head to the abdominal cavity (to prevent the occurrence of hydrocephalus noted above) (Waitzman et al., 1996).

Concurrent disorders are treated as needed, including dialysis or kidney transplant for patients with severe kidney disease, and surgery to fuse the vertebrae for patients with scoliosis (Waitzman, et al., 1996).

III.6.A.5 Prognosis

Spina bifida usually results in permanent disabilities of some type; these may be severe (e.g., paralysis). Social isolation is common, and employment prospects for adults are reduced. Even with appropriate medical treatment, children with spina bifida have a shortened lifespan. Ongoing medical treatment may be required, including replacement of shunts and treatment of kidney and urinary problems (Waitzman et al., 1996).

III.6.B Costs of Treatment and Services

III.6.B.1 Methodology

Chapters III.3 through III.8 of this handbook use cost of illness estimates developed primarily by Waitzman et al. (1996). Waitzman et al. used the same methodology to estimate the costs incurred by individuals with spina bifida as for all the birth defects for which they estimated costs. The methodology and relevant considerations are detailed in Chapter III.3, including discussions of direct and indirect costs, prevalence versus incidence, incremental costs, and concurrent effects. The analytic method, the sources of data, and the limitations of the Waitzman method are also discussed in Chapter III.3. The methodology is outlined briefly here.

Link to Chapter III.3

To estimate the lifetime medical costs incurred by an individual with a birth defect, Waitzman et al. estimated the average lifetime medical costs for an individual with the birth defect. From this value, the authors subtracted the average lifetime medical costs for an individual without the birth defect. Because they estimated lifetime costs, they used an incidence-based approach. Ideally, they would have tracked the costs of the cohort members over time, until the death of the last cohort member. Because the members of the cohort were born in 1988, however, this tracking was not possible. Instead, estimates of the costs incurred at each age were based on estimates of per capita costs in the prevalent population of that age (see Chapter III.3, Section III.3.B.1.2).

Link to Chapter III.3, Section III.3.B.1.2

This method has two important implications. First, Waitzman et al. estimated the costs incurred by individuals with birth defects, including all medical costs incurred, rather than the cost of the birth defect per se. These cost estimates therefore include the costs of concurrent effects (unlike the costs reported for many of the diseases in this handbook). This

method yields a more comprehensive assessment of total costs than would be obtained if only individual effects were evaluated. This method is of particular use in valuing the avoidance of birth defects because they very frequently occur in clusters within an individual. As Waitzman et al. note, however, the costs of associated anomalies are included as part of the estimate of the costs incurred by an individual with a given birth defect. These cost estimates therefore cannot be aggregated across birth defects because of the possibility of double counting.

Second, the Waitzman et al. method estimates the *incremental* costs for individuals with birth defects — that is, the costs above and beyond the average costs that would be incurred by individuals without the birth defect.

Waitzman et al. (1996) estimated three categories of costs incurred by individuals with limb reductions: direct medical costs, direct nonmedical costs, and indirect costs.[2] Direct medical costs, specifically inpatient care, outpatient care, pharmaceuticals, laboratory tests, X-rays, appliances, and long-term care are included in the cost estimates shown in this and other chapters (Chapters III.3 through III.8) based on the work of Waitzman et al. Nonmedical direct costs, specifically developmental services, and special education are also included in this handbook.

The Waitzman estimates of the costs incurred by individuals with limb reductions are based on the costs of this birth defect in California across many ages, and its occurrence in a large cohort of children born in California in 1988. California's ongoing birth defects monitoring program provides an excellent source of data. The California data sets were linked with other national data sets so that Waitzman et al. could estimate the incremental costs associated with spina bifida.

The method of calculating the expected lifetime incremental costs for an individual with a birth defect — i.e., the average lifetime cost per case — is the same for all the birth defects considered by Waitzman et al. The expected per capita cost at age *i*, PCC_i, for an individual born with the birth defect is the probability of surviving to age *i* (among those individuals born with the birth defect), ps_i, times the per capita cost among individuals who do survive to age *i* ($PCPREV_i$, measured in the prevalent population):

$$PCC_i = (ps_i) \times (PCPREV_i) .$$

Waitzman et al. estimate per capita costs in the prevalent population of age *i*, $PCPREV_i$, in two different ways, depending on data availability (see Chapter III.3).

[2] Indirect costs are not generally discussed in this handbook and so are not included in this chapter. The reader may wish to consult Waitzman et al. (1996) for information on these costs.

Link to Chapter III.3

The present discounted value of expected per capita lifetime costs of the birth defect, PCCOBD, is just the sum of these expected age-specific per capita costs, appropriately discounted (as explained more fully in Chapter III.3):

$$PCCOBD = \sum_i PCC_i/(1+r)^i .$$

III.6.B.2 Results

Waitzman et al (1996) estimate the total lifetime medical costs incurred by individuals with spina bifida according to the methodology outlined above. The following tables outline the various costs, updated from 1988 to 1996 dollars based on the medical care cost component of the Consumer Price Index (1996:1988=1.6465). Table III.6-1 shows the annual per capita medical costs incurred by individuals with spina bifida by age group.

Table III.6-1: Annual Per-Capita Medical Costs of Spina Bifida by Age Group (1996$)

Condition	Age 0-1	Age 2-4	Age 5-17	Age 18+
Spina Bifida	$34,013	$14,924	$13,208	$4,194

The medical cost of the average population was then subtracted from these costs to obtain incremental costs. Waitzman et al. (1996) discounted these costs using three different discount rates: two percent, five percent, and ten percent. Although these discount rates do not match the standard EPA rates used in many other chapters in this handbook (zero percent, three percent, five percent, and seven percent), there is insufficient information provided in Waitzman et al. (1996) to allow a conversion to discounted costs using standard EPA discount rates. This problem exists in all chapters based on the Waitzman et al. data (i.e., Chapters III.3 through III.8).

The present discounted values of average per capita lifetime incremental costs, using discount rates of two percent, five percent, and seven percent, are listed in Table III.6-2 below. Direct medical costs and direct non-medical costs, including developmental services costs and special education costs, are listed separately. The sum of per-capita direct medical and nonmedical costs provides an estimate of the total per-capita costs incurred by individuals with spina bifida.

Table III.6-2: Per-Capita Net Medical Costs, Nonmedical Costs, and Total Costs of Spina Bifida (1996$)			
Cost Element	**2%**	**5%**	**10%**
Net direct medical costs	$210,747	$163,000	$123,485
Net direct nonmedical costs			
Developmental Costs	$2,694	$1,635	$1,004
Special Education Costs	$50,719	$38,298	$25,155
Total Costs	$264,160	$202,933	$149,644
The costs presented in this chapter were current in the year the chapter was written. They can be updated using inflation factors accessible by clicking below. *Link to inflation factors*			

III.6.B.3 Other Studies

Waitzman et al. present a study by Lipscomb (1986) that used an incidence approach to estimate the total lifetime costs per individual of spina bifida based on data gathered from individual reviews of clinical records in North Carolina in 1985. Waitzman et al. adjust the Lipscomb estimates to account for differences in medical care prices. They deflate their California estimates by the difference in the Employee Compensation Index between California and the nation. To account for differences in the base year they adjusted the North Carolina estimates to 1988 dollars. While there is some variability in the cost distribution across age groups, the total cost estimates are strikingly similar; Waitzman et al. estimated total lifetime costs per individual of $36,529 and Lipscomb estimated total costs of $34,949 in the U.S. in 1988.

III.6.C Conclusions

The results based on the Waitzman et al (1996) work are recommended for use in benefits valuation. The Lipscomb work uses a smaller database and older data. The similarity of the two independently researched results lends credibility to the cost estimates.